ALS United

Advocacy Bulletin

Quarterly advocacy news, policy updates, and action opportunities

WELCOME TO OUR

Quarterly Advocacy News

CEO's Message

Welcome to the second edition of ALS United's advocacy newsletter. This quarter, ALS United advocates and member organizations brought the urgency of ALS directly to Washington, D.C. during ALS Awareness Month, with advocates from across the country participating in more than 40 congressional meetings, a Capitol Hill briefing, and a national advocacy effort focused on research, care, expanded access, veterans, and federal funding.

That is what makes ALS United's advocacy different. Our work does not begin with policy ideas in Washington. It begins with people living with ALS, caregivers, families, clinicians, and local organizations serving communities every day. Their experiences shape the priorities we bring to Congress, federal agencies, and national partners.

This edition highlights a busy and meaningful quarter, from ACT for ALS reauthorization moving through Congress to 2027 budget priorities, federal agency engagement, and continued work to protect access to care for people living with ALS and their families. Thank you for being part of this work. Every meeting, message, story, and shared experience helps shape the policies that affect people living with ALS and their families.

Warm regards,

Jerry Dawson
President & CEO

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ALS United Advocates Bring Community Priorities to Washington, D.C.

During ALS Awareness Month, advocates from across the country came to Washington, D.C. for ALS United's advocacy fly-in and Hill Day. Advocates participated in a Capitol Hill briefing, gathered for a training session, and took part in more than 40 meetings with congressional offices.



The week was focused on bringing the experiences of people living with ALS, caregivers, families, clinicians, advocates, and local ALS organizations directly into federal policy conversations. In meetings on Capitol Hill, ALS United advocates discussed several key priorities, including reauthorizing ACT for ALS, supporting the ALS Better Care Act, and advancing federal funding for ALS research and programs serving the ALS community.

This Hill Day came at an important moment. Congress is actively considering ACT for ALS reauthorization, federal budget decisions are beginning to take shape, and ALS Awareness Month gave the community an important platform to remind policymakers that ALS requires urgency.

ALS United is grateful to the advocates, member organizations, and congressional offices who helped make these conversations possible. If you weren't in D.C. with us, you can still make your voice heard by telling your members of Congress to prioritize ACT for ALS reauthorization and pass the ALS Better Care Act through ALS United's advocacy action alerts page.



ACT for ALS Reauthorization Introduced in House and Senate

ACT for ALS reauthorization continued moving forward this quarter, with bipartisan legislation introduced in both the House and Senate and a key House Committee expressing unanimous support for the bill. The Accelerating Access to Critical Therapies for ALS Reauthorization Act of 2026 would extend a landmark federal initiative that has helped strengthen ALS research infrastructure and expand access to investigational therapies for people living with ALS.



Since its enactment in 2021, ACT for ALS has supported open data resources, natural history and biomarker research, coordinated public-private efforts, and NIH-funded Expanded Access Programs that allow people who may not be able to participate in traditional clinical trials to pursue investigational therapies while contributing to the evidence base needed to move ALS science forward.

This matters because most people living with ALS still have limited treatment options, and many are excluded from clinical trials because of disease progression, geography, restrictive eligibility criteria, or other barriers that make participation impossible. ACT for ALS was designed with those patients in mind, pairing expanded access with the research tools, data systems, and shared infrastructure needed to make ALS research more coordinated, efficient, and responsive to real-world patient needs.

Reauthorization is critical because key ACT for ALS programs and authorities are set to expire in September 2026. ALS United will continue urging Congress to move quickly and provide the stability needed to sustain these critical programs for people living with ALS and the researchers working to end this disease. Supporters can help keep this progress moving by asking their members of Congress to support ACT for ALS reauthorization.

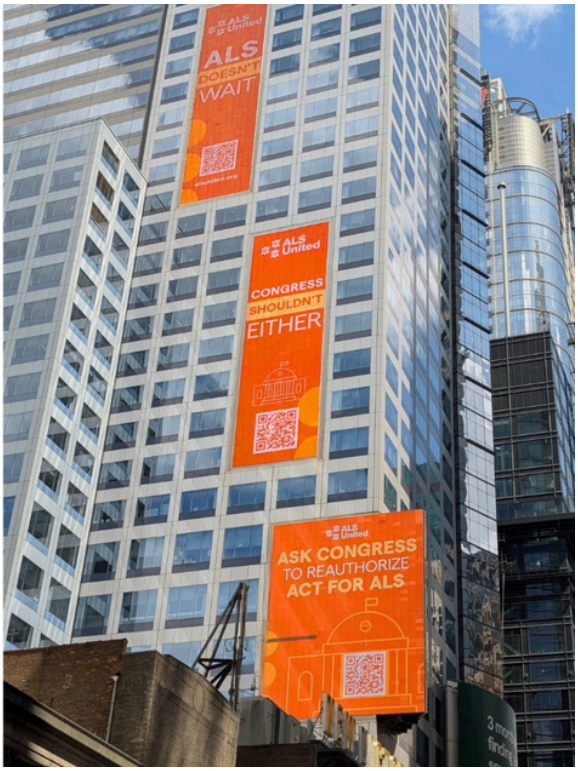
Stakeholders Unite in Support of Defense Health Research Funding

ALS United joined a broad coalition of health, research, and patient advocacy organizations in urging Congress to strengthen medical research funding at the Department of Defense. This funding supports research that can benefit service members, veterans, military families, and the broader public. For the ALS community, that connection is especially important because veterans are more likely to develop ALS, and Defense Department research has helped advance ALS science.

Alongside the Defense Health Research Consortium, we're urging Congress to restore and strengthen these research programs after recent funding reductions threatened progress across many disease areas. The request includes support for the Department of Defense's ALS Research Program, which funds high-impact research focused on understanding ALS and accelerating the search for effective treatments. ALS United will continue working with partners to sustain promising science and keep the needs of veterans and families at the center.

Act for ALS Reauthorization Ad Featured in Times Square

As ALS Awareness Month began, ALS United brought one of the community's top federal priorities to Times Square, sharing an ACT for ALS message where the world is watching. The ad focused on the need for Congress to pass the ACT for ALS Reauthorization Act before key authorities expire on September 30. The campaign helped connect national awareness with a clear policy priority at a critical moment for people living with ALS and their families.



ALS Awareness Month is a time to help more people understand the urgency of this disease and the work still ahead. By placing this message in one of the most visible public spaces in the country, ALS United helped remind the public and policymakers that awareness must be connected to meaningful action for people living with ALS and their families. Supporters can help build momentum by asking Congress to pass the ACT for ALS Reauthorization Act.

Justice for ALS Veterans Act Considered by House & Senate Committees

For veterans and their families, an ALS diagnosis can come after years of service and sacrifice. When ALS is recognized as connected to that service, surviving spouses should not face a benefit rule that ignores how quickly this disease can move. Today, families can be denied increased survivor compensation because the veteran did not live long enough with a total disability rating to meet an eight-year requirement. That eight-year standard simply does not make sense for a service-connected disease where the average life expectancy is often only two to five years after diagnosis.



That is the problem the Justice for ALS Veterans Act is designed to fix. In February, the House Veterans' Affairs Committee considered the Justice for ALS Veterans Act, and in April, the Senate Veterans' Affairs Committee took up the companion proposal, bringing important attention to a benefit gap affecting military families impacted by ALS. ALS United submitted statements to both committees urging Congress to ensure that surviving spouses are not penalized simply because ALS progresses too quickly for families to satisfy an arbitrary timeline. Military families who have already carried the burden of service and ALS deserve fair treatment under VA survivor benefit policies. Advocates can ask Congress to support the Justice for ALS Veterans Act and help ensure surviving spouses are treated fairly.

ALS Community Outlines 2027 Funding Priorities for Research, Care, and Federal Programs

As Congress begins work on the 2027 budget, ALS United joined organizations across the ALS community in urging continued federal investment across the full ALS research and care ecosystem. The community funding request calls on Congress to support key ALS priorities across NIH, FDA, the Department of Defense, CDC, ARPA-H, and the Department of Veterans Affairs. These programs support therapy development, expanded access, clinical research, data collection, public-private coordination, and care for veterans living with ALS.

Key 2027 funding priorities include:

- At least $100 million for ACT for ALS programs
- $80 million for the Department of Defense ALS Research Program
- $20 million increase for NIH ALS research
- $15 million for the CDC National ALS Registry and Biorepository
- Sustained $30 million support for ARPA-H ALS research
- $9 million to help establish at least ten ALS Research, Education, and Clinical Care Centers within VA

These investments matter because ALS research depends on continuity. Federal funding helps sustain the infrastructure needed to accelerate therapy development, collect and share data, expand clinical trial capacity, strengthen care for veterans living with ALS, and keep promising research moving. Supporters can contact Congress and urge continued investment in ALS research, care, data collection, expanded access, and federal programs serving the ALS community.

FDA Releases ‘Plausible Mechanism’ Framework for Individualized Therapies

FDA released draft guidance on a new “Plausible Mechanism” Framework, which is intended to help support therapies designed for very small groups of patients with specific genetic conditions. For the ALS community, this could matter because some forms of ALS are tied to specific genetic changes. In those cases, a potential therapy may be designed for only a small number of people, making traditional large clinical trials difficult or impossible. A more flexible FDA pathway could help promising individualized therapies move forward when the science is strong and the patient population is extremely small.

ALS United submitted comments encouraging the FDA to make clear that the framework can apply to genetic subsets of ALS when the relevant science supports it. At the same time, ALS United emphasized that faster access must still come with strong safeguards. Patients and families need confidence that therapies are being evaluated carefully, that safety is closely monitored, and that early biological signals are connected to meaningful patient benefit whenever possible. The goal is a framework that is both practical and responsible: one that helps reduce unnecessary barriers for highly targeted therapies while preserving the trust, transparency, and safety expectations that people living with ALS and their families deserve.

Upcoming Events

Lou Gehrig Day

Major League Baseball Parks

June 2, 2026



For more information or to get involved in advocacy efforts, please feel free to reach out to us at:

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Your participation and support are crucial in our continued efforts to improve the lives of those affected by ALS. Whether you are a person living with ALS, a caregiver, a healthcare professional, or an ally, your voice can make a difference.

Together, We End ALS!®